Dementia and Family

The Role of Burdening in Families Caring for Elderly Living with Dementia in the Initiation of Long-Term Residential Home Placement

Thesis of Doctoral Dissertation

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Abstract

In my doctoral dissertation, I will explore the background of burdening of caregiving families, furthermore, the pivotal factors of institutional placement through an empirical analysis. What I was curious about was that critical decision making period when the caregiving families would opt for long-term residential placement. In the last years, the international researches have turned towards families caring for elderly people with dementia /see the works of Zarit et al. 1985, 2005; Aneshensel et al. 1995; and Kaplan 1996/. The majority of these researches analysed the stress burden of the caring family member and its consequences, role conflicts, and the tensions in the caregiving family (Zarit et al. 1985; Aneshensel et al. 1995; Kaplan 1996; Zarit et al. 2005). The revelation that in terms of Romania, we know nothing or almost nothing about the burden of families caring for elderly people with dementia and its effect on the primary carer, played was an important factor in the choice of topic. This is why, in a vast empirical analysis, in Transylvania, 50 interviews and questionnaire surveys were made with people caring for elderly with dementia in their own homes and 50 families whose relatives with dementia have been moved to a long-term residential home in the past 12 months from the time of the survey. Gathering data took three years (2015–2017). By publishing the results of the survey, I would like to unfold the factors of burden in the caregiving families, the hardships of caregiving, and also, factors that decisively contribute to long-term residential home placement. The result of this analysis is novel in Romanian and Hungarian terms, since *there are no similar researches about the burden of caregiving families*, and also, it accommodates the internationally known researches (Zarit 1985; Aneshensel 1995; Kaplan 1996; Zarit 2005). The research included the inquiry interview with the primary caregiver family member, in which we assessed the functional barriers and the psychosocial difficulties (Szabó 2000). The analysis of the levels of social skills was built upon this, and it unfolded the main characteristics of self-sufficiency, existing social skills, and social adaptation. This survey pointed out the everyday tasks in which the client requires help. With regard to family care, we have also analysed the independent living ability of people with dementia. These three angles offered the guidelines for the assessment of "objective burden" of the caring family member.

Reviewing the distribution of caring tasks within the family is based on this, which helps us finding out who the key persons are, the ones undertaking the primary caregiving duties. For analysing the formation of roles within the family, we have devised our own criteria (Szabó–Kiss 2015). Starting from the objective burden, in regard to the "subjective burden", we have

obtained valuable indications about the emotional effect of caregiving family member. The detailed assessment of self-sufficiency through which we have analysed the measure of functional degradation of people living with dementia, was added to the devices of the analysis (Szabó 2000). The internationally approved scale of memory and behavioural problems (Zarit 1985) is connected to this, which measures the distractive attitude of the person living with dementia and its effect on the primary caregiver. The survey of the primary caregiver's burdening is also connected (Zarit 1985), and so is the assessment of the negative and positive attitude towards the caregiving tasks (Farran et al. 1999). A six-step focus group is added to the devices of the research, in which the primary caregivers, by hearing each other's cases and following thematic questions, open up more easily about the critical periods of caregiving and the pivotal factors of institutional placement. Through short case illustrations related to the topic, the dissertation shows how people living with dementia gradually lose control over their lives, their memory, and their ability to orientate themselves in time and space. These case illustrations reflect accurately the strains of the primary caregivers. The caring tasks of the caregiving family members sometimes seem inhuman.

Through an extensive review of the hardships of caregiving, the analysis also illuminates the caregivers' experience of a beloved family member being diagnosed with dementia. It points out how they face caregiving challenges, and where the critical burdening point is, in which the caregiving family members make up their minds and place the person living with dementia in a residential home.

While examining the burdening of the caregiving family members, my first discovery was that the task of caregiving is not distributed evenly in the family. We usually find that during the emergence of the associated hardships, in a significant proportion, a "**primary caregiving family member**" undertakes the tasks, in most cases, a daughter, sometimes sharing the task with other family members, which hence become secondary caregivers.

Dividing roles and tasks, and their weight upon the primary caregiver family member's shoulder is a good scale of the role burden, primarily seen in assessing the burden of the primary caregiver family member. The seriousness and the frequency of the "distractive behaviour" of the person living with dementia, and the caregiver's reactions to these occurrences are pivotal factors in the formation of the latter. I have analysed this mainly regarding the formation of the caregiving family member's roles. In the focus group research,

I was curious the subjective, emotional experiences of the families caring for people with dementia – besides the objective, quantitative data.

When summarising the research results, we can identify different characteristics of the decisive factors in residential home care, and while the caregiving family members face a series of behavioural problems and continuous loss caused by dementia, they do not have experience; they are left without support, while facing their impotence, often, the loss of hope.

Factors contributing to the decision: facing the diagnosis, perplexity, and the impaired opportunities of the caregiving families. For the families in this situation, a **critical point** is that caregiving family members have little professional background, and they lack the appropriate resources, the supportive background, while gradually they turn into practicing nurses/carers through the experiences obtained in the process of caregiving. Working with people living with dementia make great demands of the caregiving family, and which goes along with giving up on their own lifestyle.

By analysing the focus group discussions, we can draw the conclusion that the caregiving family members live through the moments of clinging to the positive moments of denial, accusing life, despair, hopelessness, fear, and also, attachment and care. On the rollercoaster of acceptance and letting go, often they live through their days while their own life crumbles.

Primary caregiving family members often lose their hope towards life and become uncertain in the caring process, because of the lack of a supportive background. They face a series of challenges daily, consorted with giving up their life goal, or workplace.

Introduction

"My mother was diagnosed with Alzheimer's. I think it's an awful disease. The person is lost in it. I don't mean anything to her. She knows that somebody is there with her, but she doesn't know that I am her daughter. She doesn't know anything, I feed her, I give her drinks, I take her on walks, and I bathe her like a baby. What can I do, she's my mother!" (Primary caregiver: Ilonka)

Caring and providing for people with dementia is one of today's greatest medical and social challenges, since families caring for people with dementia live through a series of tests and burdens regarding their quality of life, caused by both the social isolation of the family, and the financial hardships (Henry Brodaty – Marika Donkin 2009). As a result of this

recognition, attention is increasingly focused on half of the caring families, more and more research data point toward the fact that the families' burden, its psychosocial consequences regarding the caring for elderly with dementia have a great influence on the families' quality of life, these factors affect the caregiving family members' psychic health (Szabó 2011, Pék 2013). In the work of assisting professionals, personal care is considered the pillar of care (Tom Kitwood 1997), but we might also ask the question: how do family members caring for people with dementia for years live through their everyday life?

In my dissertation, besides theoretical and methodical statistical indicators, we find out about the hardships of working with people with dementia, the amplification of burden, the risk factors of caring, and the factors of opting for residential home care, **through the voice of the caregivers.**

My dissertation has three main chapters; the case presentations made during the research are related to these.

The first chapter of the dissertation expands the demographical changes and contexts, and also, the frequency of dementia. Based on Easter European and local samples, I focus on the changes concerning the caregiving families. The dissertation presents the Romanian Alzheimer's Alliance, the measure enacted for the financial aid of the patients, and the local social service system, too, as a defining social and institutional context of the research, highlighting the Caritas Alba Iulia's Saint Elisabeth Nursing Home.

In the theoretical chapter, I defined the relevant basic terms of the topic. I considered useful writing briefly about ***dementia*** itself, its symptoms and its effect in order to make understanding the affected people's hardships and the risk factors of burden on the caregiving families easier. From the point of view of the near-home care, I have approached dementia as a challenge. Within this, I emphasized memory and behavioural problems, care conditions, caregivers' skills and motivation (Tariska 2003). The first chapter includes presenting family roles and ***caregiving challenges***, underpinned by case presentations. Here, we find out about the path that leads to the closest family member becoming an informal helper, and also about the factors confirming the positive attitude of the carers, hence giving strength for caring (Farran et al. 1999). During the research, our attention, besides the task undertaking of the families, was turned towards the physical, psychical, and social burden on the family. A major element of the research, besides the aforementioned, is the appointment of ***the primary caregiving family member***, the path leading to this, combining their own workplace and

family responsibilities. Along the ***caregiving form***, I could not leave out the stress burden, the role tensions of the carers, and the shift of roles (child or parent, wife or mother, grandchild or carer). Besides the objective (measurable) burden formulated by Zarit (Zarit 1985), the analysis of subjective (perceived) burden is also important, including the distribution of roles, the ***coping*** of caring families with their care difficulties, and ***exposing the decision to opt for*** residential home placement (Szabó–Kiss, 2015). In the **second part of the dissertation** I presented the research programme, the criteria for selecting a focus group, the implementation of the research and its methodological tools, and focus group research. **The third part of the dissertation** includes the results of the quantitative and qualitative processing based on the hypotheses, and it also discusses the focus group meetings by analyzing personal narratives. After the conclusion and the professional recommendation, the appendix contains a description of the methodological toolkit and a few tables containing test results. In order to protect the patients and the caregiving families, I have followed the ethical prescriptions of the assisting work. I used fictitious names when presenting cases and I did not disclose their actual place of residence. I presented the cases that, together with the theoretical background, bring the reader closer to practice, to reality, and which reinforce the depth of the present research. By doing so, they explore the difficulties of carers and the factors of opting for residential home placement.

The aim of the research and hypotheses

The aim of my research was to obtain new information about the burden of caregivers of people living with dementia. I intended to identify the stages of coping in families caring for people with dementia, I tried to find out what strategies they used, how the roles were shaped, how they lived through the changes in a beloved person, and also, where that critical burdening point was in which the family decided for institutional care. The research unfolds what the carers are missing from the social service system. The broader objective was presenting and publishing the results of the research to the social service system and society. Placing an elderly family member into a residential home is a critical event in a family's life, preceded by a period overwhelmed with tension, conflicts. I suppose that caregiving families being left alone with this stressful task plays a significant part in this, and services, supportive backgrounds that would aid the familial care for people living with dementia are also lacking.

The hypotheses of the research

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1st hypothesis: from the caregiving families' point of view, the most significant change in the degradation process would be the deterioration of the self-care ability and the basic social skills of the family member with dementia. As a result of this, the increasing caring burdens contribute fundamentally to opting for residential placement.

2nd hypothesis: during the caring, the cognitive decline is represented by memory deterioration as an "axis symptom", and also, the seriousness of the "disruptive behaviour", appearing as a result of dementia /BPSD/ poses one of the greatest challenges, and their aggravation has a direct part in initiating institutional placement.

3rd hypothesis: the serious increase of the caring tasks of the primary caregiving family member, the invasive presence of the role as a caregiver, and confronting loss all cripple the everyday functioning of the family, and this untenable situation has a decisive part in institutional placement.

4th hypothesis: I assume that in spite of the hardships, the caregiving families endeavour keeping the elder person in need for care in family. I analyse the "resilience factors" that are factors of the successful coping related to the caregiving tasks.

5th hypothesis: I assume that there is a difference in the extent of burden in families initialising institutional placement and in families assuring familial care, and this difference can be traced in regard to my interviews and surveys.

The aforementioned factors, the constellation of more than one factor all have a pivotal role in opting for institutional placement – as a result of the ever more unfavourable conditions resulting from dementia.

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Metaanalysis

The research concerning caregiving families is based on three significant works: the analysis of objective and subjective burden, whose starting point is the consultation model presented by Zarit in 1985 aimed at helping the caregiving family. The team of California University also studied the hardships of the caregiving family member, almost ten years later (Aneshensel et al. 1995). The theoretical ground of the study was the “stress process model” elaborated by Pearlin. Montgomery and Kosloski’s role identity theory has also been fundamental to my own research, since it makes the often dramatic role changes in the caregiving family measurable (Montgomery–Kosloski 2013). The dissertation talks about all three significant researches.

Methodical toolkit

During the research, in the framework of an empirical analysis, interviews and surveys were made with the relatives figuring as primary caregivers of elderly people living with dementia in their own homes, in a quantitative and qualitative analysis. The research examines the burden of caregiving families, but it also considers discussing with the recipients of caregiving. The larges location of the research was Transylvania, where we have assessed elderly people diagnosed with dementia, which applied for the Saint Elisabeth Nursing Home

of the Caritas Alba Iulia in Gheorgheni, and their families, with the inclusion of family physicians and psychiatrists. Concerning the distribution of the assignments, the research spread over 11 counties of the country: Harghita County 33%, Brașov 16%, Mureș 11%, Alba 9%, Cluj 7%, Satu Mare 6%, Covasna 5%, Sălaj 4%, Sibiu 3%, Bistrița-Năsăud 4%, Bihor 3%. Concerning the ages, the present specimen has 15 people between the ages of 65-78, 48 people between the ages of 75-84, and 25 between the ages of 85-94. Out of the 100 patients, 8 have primary or less education, 28 persons attended primary school, 17 persons were trained in vocational training, 23 persons attended secondary school, 3 persons attended college, 10 persons went to university. Marital status: 4 married, 39 married, 4 in domestic partnership, 15 divorced, 38 widows.

This research does not cover medical-diagnostic details, it does not communicate the full interview, however, it explores the behavioural changes of people as results of the dementia, and the effect of these changes, the extent of burden from the caregiving families' point of view.

In order to gain an in-depth knowledge of the caregiving families' burden, I have utilised an interrelated analysis toolkit, the majority of which is connected to the analysis tools known from the international researches. The analysis, by unfolding the many-layered caregiving hardships, illuminates the caregivers' experience of a beloved family member being diagnosed with dementia. How do they face caregiving challenges, and where the critical burdening point is, in which the caregiving family members make up their minds and place the person living with dementia in a residential home. In my dissertation, besides theoretical and methodical statistical indicators, we find out about the hardships of working with people with dementia, the amplification of burden, the risk factors of caring, and the factors of opting for residential home care, through the voice of the caregivers. When mapping the families to participate to this programme, I chose the ones that have a person suffering from moderate to advanced dementia (50), furthermore, they have moved into the home in the last year from the assigning (50). Hence, the research is somewhat retrospective. The research started in the summer of 2015 and ended in May 2017. The questionnaires were sent to the distant relatives by email. Research started in the summer of 2015 and ended in May 2017. The questionnaires were sent to the distant relatives by email.

In the framework of the survey, I have conducted grounding interviews with the primary caregiving family member in order to assess functional barriers and psychosocial difficulties

regarding the analysis of modified ADL (independency), the scale for measuring modified IADL (independence of daily activities; Szabó L. 2003), social skills assessment survey (Szabó L. 2003), assessing self-sufficiency (Szabó L. 2000), memory and behavioural problem scales (Zarit 1985), the assessment of the primary caregiver family member's burden (Zarit 1985), the evaluation of the positive and negative attitudes towards caregiving (Farran et al. 1999), as well as the changes of the family roles (Szabó–Kiss 2015). All this was accompanied by a six-session focus group research. I have used the SPSS program for processing data.

Questions that have been processed in focus group research:

1. How do you remember finding out the diagnosis? What did you experience then?
2. What previous knowledge and information have you had about dementia?
3. How do the consequences of the deterioration process affect the everydays of the caregiving?
4. How did the disruptive behaviour affect you? How did you handle it?
5. How did you try to get ahead?
6. How did the personality changes, relationship losses caused by deterioration affect the kept family member?
7. What resources, what supportive background was available for the caregiving family member?
8. In your opinion, what does the social service system lack?

Observations

Analyzing the contents of conversations and deep interviews in the focus group the conclusions can be summarized in 3 statements:

1st Statement: during the focus group sessions, I have realized that caregiving family members have little professional background, while gradually they turn into practicing carers through the experiences obtained in the process of caregiving.

2nd Statement: "Primary caregivers live their everyday lives on a rollercoaster of insistence, denial, accusation of life, despair, hopelessness, fear, acceptance, and letting go", often while their own lives crumble. While seeking for experiences supporting the positive coping process, the narratives of the relatives have three common denominators: love, holding on to faith, and the recollection and guarding of beautiful memories. According to them, they have

lost hope many times, they have become insecure about the changed personality of the patient, and it was hard losing them alive.

Theses, results

In my starting hypotheses, I have formulated a series of assumptions; a major part of these can be underpinned by bibliographical pivots, by the results of previous researches. The patients (N=100), based on their general physical condition: 4 people are seriously weakened in/patients; 18 people from the SENH (Saint Elisabeth Nursing Home) and 12 people from the CH (client's home) are weakened inactive, 20 people from the CH are in average condition, 46 people are in good physical condition, 30 out of which live in the SENH. Out of the seven factors of the cognitive functions' condition we have examined the following: proper knowledge of personal data: name, address, family members' data, life history nodes, timely placement of important life events, self-assessment, grasping the essentials, good overview – discretion, action organization, decisiveness, purposeful performance, money management memory. Who visited them? Data about the ability to keep things in mind, correct speech comprehension and expression, choice of the three options available (retained, partially retained, lost); apparently both in the case of people living in their own homes (CH=38), and is residential home (SENH=40), the most prominent problems are related to money management (*how much is their pension? how much is their electricity bill, heating? how much do they spend on food, medicine etc.?*). In the case of the *memory* factor, this function is retained only in 4 cases, in 36 cases, it is partially retained, and it is lost in 60 cases (SENH=32; CH=28).

According to the modified ADL (cleaning, dressing, eating, toilet use, incontinence, transport) and IADL (phone use, out-of-home transport, shopping, cooking, household chores, minor repairs, washing, taking their medicine, cash management) scales, both surveys found that the majority of the patients is not capable of independent living anymore. As a result, the caregiving family members have to take over the patients' everyday life tasks.

As the deterioration process advances, we can find the ever increasing caregiving burdens and "disruptive behaviour" harder and harder to handle. The research identified differences in the two variables between the Saint Elisabeth Nursing Home (SENH) and the Client's home (CH).

Caregiving family members face increasingly more and unmanageable forms of disruptive behaviour, e.g. "wandering or getting lost": in the client's home, out of the 50 families interviewed, in 14 cases, the person with dementia needs to be locked up to prevent wandering.

Based on the focus group discussions, it can be said that this is one of the main reasons, difficulties, which proves to be pivotal in opting for residential home placement. Between the two variables, regarding the initial hypothesis, the result of the empirical examination proves that unmanageable disruptive behaviour is more likely to be present in families that have already placed their relative in institutional care, than in the case of people being cared for in their own homes.

As I have formulated in the aforementioned initial hypothesis, the caregiver family member goes through a "caregiving career" over the various stages of coping during caregiving; this can seriously affect their roles in the family, and it can often be the source of conflicts. The results show higher burdening in the case of caregiving family members caring for their relative in their own homes, that in the case of the caregivers of people living with dementia in residential homes. The growth of burdening, the analysis of roles (Szabó–Kiss 2015), based on four possible answers (there is none; moderate; significant; high): I found that in the client's home, in four cases there is none, it is moderate in six cases, significant in 26 cases, and high in 14 cases.

According to the results found in the Saint Elisabeth Nursing Home, in two cases, there is no higher burdening, it is moderate in four cases, however, in 44 cases, burdening is significant, and high in four families. When the patients lose control over their lives, and they are unable to control their own lives, in most cases, the primary caregiver, the legal representative, the guardian family member takes over the roles, which in itself can be burdening, e.g. making decisions in others' place, because we never know whether if the family member we care for was able to make decisions, what would he decide about his lifestyle. According to the results of the analysis, the highest role tensions: household keeping (72 cases), caring (68 cases), offering support (64 cases), making decisions (60 cases), work and home care (48), administration (46), and in 40 cases, the personal relationship.

The result of the first hypothesis: from the caregiving families' point of view, the most significant change in the degradation process would be the deterioration of the self-care ability and the basic social skills. The growth of the caregiving burden resulting from this has

a pivotal role in opting for institutional placement. Based on the results of an empirical analysis aimed at self-care ability comparing people with dementia living in the Saint Elisabeth Nursing Home for a year to people being cared for in their own homes, based on four factors: 1. household, 2. home-based activities, 3. out-of-home activities, 4. daily living, there are significant differences. I have observed that elderly people living with dementia in residential homes are less likely to embrace their everyday life tasks necessary for sel-care, which most likely influenced the caregiving family members to decide for residential home placement.

In my second hypothesis the cognitive decline is represented by memory deterioration as an "axis symptom", and also, the seriousness of the "disruptive behaviour", appearing as a result of dementia poses one of the greatest challenges, and their aggravation has a direct part in initiating institutional placement. One of the most typical disruptive symptoms is "wandering-getting lost", which is a risk factor from the caring families' point of view too. The fact that a person living with dementia wanders off more than three times per week points at high burdening from the caregivers' point of view, it can involve anxiety, fear, and also, it can be a source of conflicts in the family. According to a statistical test, there is a significant connection between these two variables: the frequency of "wandering and getting lost" and "do you wish to leave caring for your relative to someone else?", and p=0,005.

In my third hypothesis, I have stated that the serious increase of the caring tasks of the primary caregiving family member, the presence of the role as a caregiver all cripple the everyday functioning of the family, and this untenable situation has a decisive part in institutional placement. During the statistical test, in regard to the location (SENH/CH), a significant correlation was found: "administration and representation of the family" $p < 0.001$, "leadership role in family roles", where $p < 0.001$, "household and partnership" $p < 0.002$. Between the variables "home-making" and "money management", the value of significance is $p<0.001$. In case of the "work and money management" and "increasing burdening of family roles", the value of the significance coefficient is $p<0.004$.

Moreover, in "home-making" and "partnership", $p<0.001$. In "caregiving" and "offering support", $p<0.002$.

Caregiving families experience a series of losses, i.e. a person lost, hopelessness, sadness, damaged life. We might ask what the caregiving family member lives through. The answer given might influence the previous relationship between the caregiver and the patient, and

also, the memory of the bygones experienced through the life arch. Out of the N=100, when analysing the sense of loss, there is a significant correlation, where $p>0.001$ in the questions "I am sad, the person I have known is gone", and "I feel that my situation is hopeless". There is also a significant correlation between the "there is no hope, I am just clinging to a straw" question and "I feel like my situation is hopeless", where $p<0.004$. In case of the questions "I miss my old life" and "I am not happy for anything", the value of the significance is $p=0.005$.

In my fourth hypothesis I assumed that caregiving families endeavour keeping the elder person in need for care in family, and I considered analysing the "resilience factors" that are factors of the successful coping related to the caregiving tasks important. Along the questionnaire, 11 questions are related to the positive feeling associated to caregiving, these can be mentioned as "resilience" factors in which we can observe what might offer strength to the caregiver. In Farran et al.'s questionnaire (1993), life, existence, relationship, aim, hope, memories, experiences, and hope appear. In a cross table, we can observe the results of the quantitative comparison between the relatives of people living in the Saint Elisabeth Nursing Home and relatives living in the client's home. They had four answer possibilities (*I disagree, I agree, I cannot decide, I strongly disagree*).

We could highlight hope, which could also be something to hold on to. As we can see, hope as a resource is highly preferred in the homes of 44 clients (CH), and it plays a significant part for relatives of people living in the Saint Elisabeth Nursing Home (SENH). But naturally, there are families more likely to become hesitative as a result of burden and loss.

Hence, these people were more likely to opt for "I cannot decide" or "I strongly disagree". E.g. in "I believe God will take care of me" (22 cases), and "caring gives my life goal and meaning" – also 22 cases of relatives of people living in residential homes (SENH), opposed to 8 people who are still caring for their demented relatives in their own homes.

Weighting shifts in both variables in the question "God will not place more upon you that you can handle", because 32 cases in the SENH definitely marked "I cannot decide", and 12 cases in the CH also "could not decide", while in 10 cases "they strongly disagreed" with the question. Based on the present research, we find how many changed, unforeseen problems and hardships are caused to the caregiving family by dementia, however, according to the research data, I have experienced that along the caregiving arch, the memory of bygones bonding the caregivers to the patients can either help, or block the assisting-caregiving work.

The attitudes of the caregivers and the patients, the common memories, family patterns, and faith in God can become crutches in bearing the everyday burdens. At the same time, we can see (*I cannot decide*), that caregiving family members often become uncertain in their faith as result of the burdens. In the questions "*common memories and experiences are important to me*" and "*caregiving made me stronger and better*", $p<0.002$. Significance value is $p=0.005$ in the variables "*helping feels good during caregiving*" and "*every day is a blessing*". In the questions related to faith, in the variables "*I believe in the power of prayer, otherwise I would be unable to do this*" and "*God is good*", the significance correlation is $p<0.002$.

In my fifth hypothesis, I assumed that there is a difference in the extent of burden in families initialising institutional placement and in families assuring familial care, and this difference can be traced in regard to my interviews and surveys. The result of the research showed a minimal differentiation in the correlation coefficients in these two variables.

$P<0.001$ in the questions "I feel like my relative demands more help that he needs" and "I feel uncomfortable about the behaviour of my relative" in the statistical test's significance analysis about the caregiving families' burdening along a multivariate significance analysis.

We can also find a significant correlation in "I feel like my relative is overly dependent on me" and "are you scared of what the future holds for you?", where $p<0.002$. In both variables (SENH/CH), $p<0.001$ in "do you feel tension when you do something around your relative?", and $p<0.001$ in "do you feel like your health has deteriorated during caregiving?".

$P<0.001$ in "do you feel like you do not have enough time for yourself because of taking care of your relative?" The analysis shows a significant correlation between "do you feel like you should do a better job in caregiving?" and "do you feel uncomfortable about the behaviour of your relative?", where $p<0.001$. Along these correlations, the research concludes that primary caregivers opting for residential home placement are starting from under a mild burden to a moderate burden, and with a growing number of cases, they are under a heavy burden, and there is some difference compared to primary caregivers working in the client's home, where burdening seems lighter according to the burdening scale's weighting.

Innovative results

This research examined the burden of caring families and the background factors of institutional placement. In Romania and Hungary, we cannot find a similar research about the burden of caring families, thus I believe that the results of the present research would be

suppletory. This examination conforms to researches conducted in the USA (Zarit et al. 1985; Aneshensel et al. 1995; Kaplan 1996; Zarit et al. 2005; Montgomery and Kosloski 2013).

Selecting the primary caregiver family member is a multi-factor process. This cue is often undertaken by the family member closest to the patient. Caregiving family members live through the changes associated with cognitive deterioration painfully. In many cases, we hear that they are shocked when hearing the diagnosis. The degradation of social skills and the adaptation of behaviour along the cognitive decline play a decisive role in the decision-making process of opting for placement. Increasing the burden triggers a series of role tensions. Based on quantitative results, household management, care, support, and decision making show high burdening.

The results of the quantitative examination, the case studies, and the focus group discussions reflect the background problems of residential home placement, and opting for residential homes. In relation to the placement decision, primary caregivers have repeatedly referred to ambivalent feelings, hence, in the presentation of cases, the causes of residential home accommodation and its decisive factors there may be a slight distortion that can be written on the self-defence mechanisms of caring families.

When assessing the results of the examination, we can identify different factors of residential home accommodation: caring family members, as a result of dementia, face a series of behavioural problems and continuous losses; they have no experience, no support, while they face impotence daily, and often, the loss of hope.

Pivotal factors of the decision: the shrinking opportunities of caring families, perplexity, the danger of giving up on their own lifestyle. We have to keep in mind the case examples in which we see that caregivers are facing even more serious problems with the progress of dementia.

In this situation, it is a critical point for families that a close family member becomes a caregiver. In addition, caregiving family members have little professional background, and they lack the appropriate resources, the supportive background, while gradually they turn into practicing nurses/carers through the experiences obtained in the process of caregiving. Working with people living with dementia make great demands of the caregiving family, and which goes along with giving up on their own lifestyle. Primary caregivers often lose hope in

life and they become uncertain in the caring process, in the lack of a supportive background. They face a series of challenges daily, consorted with giving up their life goal, or workplace.

Conclusions, recommendations

Besides these pivotal factors and burdening, one of the most important pillars is referring to family bonds, e.g. faith, old memories, family patterns, family links, and love. Based on the research results, we see that caring for elderly people living with dementia often exceeds the resources of the caregiving families, and they opt for residential home accommodation under the pressure of caregiving. In today's society, in Romania, prejudice and scandalizing coming from close family members, neighbours, and wider milieu is still a thing against families placing their relatives into residential homes (see the case presentations).

Along with these, considering the results of the research, we must strive to learn the international "good practices" of professional policies, social service systems, and education in order to keep people living with dementia in their own homes for as long as possible. Concrete steps are required to support caring families and patients. The 2009 report of Alzheimer's Disease International published the data of worldwide prevalence of dementia obtained from 154 worldwide studies. In 2010, the proportion of people with dementia was estimated at 36 million, by 2030, in 20 years it would almost double, to 66 million, and by 2050, to 115 million (Alzheimer's Disease International. The global voice in dementia / The Global Impact of Dementia [2010–2050]).

The results of this research, the burden of caring families, tell the society that strong, committed inter-professional co-operation and collaboration is required in this area. First of all, strengthening the interoperability between professionals and caring families, training of caring family members would be needed to prepare for the course of dementia. Creative environmental measures would be a need, such as dementia-friendly places for pedestrians, parks, community spaces, Alzheimer café.

Transylvania lacks a residential prevention program, dementia-based life counseling, support group, support club for family members caring for people with dementia; temporary relief 'respiro programmes' would also be needed besides long-term, institutionalized care, and any alternative solutions that provide part-time services to families during the care of the person with dementia.

I hope that the results of my research, recognizing the burdening of caregiving families would draw the attention of people practicing either in society, in policy, and in the field of assisting profession, or in education or in the field of practical work that by thinking together, we could find, in the spirit of multidisciplinarity, the opportunities to improve the quality of life for people with dementia and their caregivers.

Cited sources

Aneshensel, C. S. et al.(1995): *Profiles in Caregiving*: The Unexpected Career Academic Press. New York.

Brodaty, Henry, MD; DSc; FRACP; FRANZCP – Donkin, Marika , BA – Psychology (Rons); Grad'DipProf Ethics 2009: *Family Caregivers of People with Dementia*

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181916/#ref37 Downloaded: November 7, 2017.

Farran, C. et al. (1997): *Theoretical Perspectives Concerning Positive Aspects of Caring for Elderly Persons With Dementia:* Stress/Adaptation and Existentialism, Copyright 1997 by The Cerontological Society of America, The Cerontologist Vol. 37, No. 2, 250–256.

Farran, C. et al. (2008): *Exploring Positive Attitudes Toward Caregiving*. In: Greene, Roberta R.**:** *Social Work with the Aged and their Famillies*, Aldin. London. 151–152.

Farran, C. et al. (2011): *Assessing Family Caregiver Skill in Managing Behavioral Symptoms of Alzheimer's Disease* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3080236/ Downloaded: April 4, 2015.

Fehér, B. (2013): A narratív segítő beszélgetés http://www.esely.org/kiadvanyok/2010_3/04feher.indd.pdf Downloaded: May 2, 2018.

Montgomery, Rhonda J. V. (2016): *Caregiver Identity Theory Overview*.

https://www.researchgate.net/publication/265260328

Montgomery, Rhonda J. V.: *Change, Continuity and Diversity Among Caregivers* http://catalogue.iugm.qc.ca/GEIDEFile/16211.PDF?Archive=193257991143&File=16211_PDF. Downloaded: July 7, 2016.

Pék, Gy. (2013): *Az idős családtag gondozásának komplexitása*. In: Kállai János, Kaszás Beáta, Tringer István: Az időskorúak egészségpszichológiája, Medicina Kiadó, Budapest. 293– 302.

Szabó, L.–Kiss, G. (2015): *A családon belüli szerepek alakulásának vizsgálata, a családi feladat és szerep megosztások és a mentális romlást követő feszültség növekedése és a szerepstruktúra átalakulás vizsgálatára adaptált vizsgálati eszköztár* Kiss és Szabó 2015./

Szabó, L. (2011): *Időskori demenciák családi, pszichológiai, és társadalmi következményei*, Akadémiai Kiadó. Budapest.

Tariska, P. (2003): *Szellemi hanyatlás idős korban*, Országos Pszichiátriai és Neurológiai Intézet, Therapia Kiadó. Budapest.

Zarit, S., Zarit, J. (1985): *Memory and Behavior Problems Checklist.* In: Zarit, Steven H., Orr, Nancy K., Zarit Judy M.: *The Hidden Victims of Alzheimer's Diseases* – New York University Press. New York. 78– 79.

Zarit, S., Zarit, J. (1985): *The Burden Interview.* In: Zarit, Steven H., Orr, Nancy K, Zarit Judy M**.:** *The Hidden Victims of Alzheimer's Diseases* – New York University Press. New York. 84– 85.

Zarit, H., Steven – Honn Qualls, Sara, (2009): *Aging Families and Caregiving*, USA.

Publications on the subject by the author

Kiss, Gabriella (2017): *A demens személyeket gondozó családok terhelődése, szerepfeszültsége, a gondozottak kognitív leépülése mentén*. Erdélyi Társadalom 15 (2), Cluj-Napoca.

Kiss, Gabriella (2017): *Együtt a demens beteggel a gondozói szerepek labirintusában. Terhelődés, veszteség, avagy a pozitív attitűd szerepe a megküzdést elősegítő folyamatokban*. Kharon, Thanatológiai Szemle, Budapest.

Kiss, Gabriella (2017): *A gondozó családok terhelődése és a családi szerepek alakulása.* Carissimi – Esély fogyatékos és egészségkárosodott embereknek. Kiadja a Szlovák Humanitárius Tanács (vydáva Slovenská humanitná rada, Budyšínska 1, 831 03 Bratislava; IČO: 17 316 014)

Kiss, Gabriella (2016): *Az idősek peremre szorulásának megelőzéséért*. Szerk, Bereczki Silvia sa. Sokarcú irgalmasság. Vallomások, interjúk, tanulmányok. Verbum, Cluj-Napoca, 237–247.

Kiss, Gabriella (2015): *Középsúlyos és súlyos demens betegek személyközpontú ellátásának módszere, családias közegben, illetve bentlakásos otthoni körülmények között.* Párbeszéd szociálismunka-folyóirat. Vol. 2. (2015.) No. 2.

Conference presentations on the subject

1. *Demencia és a család. A gondozó családok terhelődésének szerepe a demenciával küzdő idősek bentlakásos otthoni elhelyezésének kezdeményezésében [Dementia and family. The role of burden on caring families in initiating residential care for the elderly]*, ELTE TáTK, Szociológia Doktori Iskola, Interdiszciplináris Társadalomkutatások Doktori Program, Évzáró Konferencia, Szarvas, 2017

2. *The Factors of Family Caregiver's decision to strive for institutional placement of the care recipient*/ Kiss Gabriella MSW, Social Worker, Mental Health Care PhD student, Eötvös Lorand University, Faculty of Social Sciences, PhD programme in Interdisciplinary Studies 31st International Conference of Alzheimer's Disease International, April 21-24, 2016, Budapest.
3. *Az idősek peremre szorulásának megelőzéséért [Preventing the elderly from being marginalized]*/ Debreceni Egyetem, Egészségügyi Kar, Nyíregyháza NYÍREGYHÁZI GERONTOLÓGIAI NAPOK VIII. 2016
4. *A családi szerepek alakulásának jelentősége a segítő munkában [The importance of changing family roles in assisting work]*/ Együtt a fogyatékkal élőkkel X. Konferencia, September 24, 2016, Miercurea-Ciuc.
5. *Önmagunk segítése a segítő munka során [Helping ourselves in assisting work]*/ Együtt a fogyatékkal élőkkel IX. Konferencia/ Apáczai Csere János Pedagógusok Háza, Miercurea-Ciuc, 2014.
6. *A demens betegekkel való munka kihívásai [Challenges of working with patients with dementia]*, Projektzáró Konferencia- Gyulafehérvári Caritas Marosvásárhely, 2014.
7. *Az időskor lélektana [The psychology of old age]*, Sokszínű Caritas, Gheorgheni, 2014.

8. *Az idősek biztonsága [The safety of the elderly]* – Nemzetközi Konferencia Kecskemét,2013
9. *Idős ellátásban dolgozók életminőségének hatása a munka minőségére [Impact of the quality of life of people working in elderly care on the quality of work]/* Gyulafehérvári Caritas, Gheorgheni, 2013.
10. *Mindennapok a demens személlyel [Everyday life with a person with dementia]*/ Gyulafehérvári Caritas Felnőtt Oktatás, Gheorgheni, 2013.
11. *A segítők lelki egészségének megőrzése – miből meríthetünk erőt? [Maintaining the spiritual health of helpers – What can offer us strength?]* Mentálhigiénés Konferencia BBTE Cluj-Napoca / Gheorgheni, 2013.
12. *Szellemileg leépült idős a családban! Mit tehetek? [A mentally declined elder in the family! What can I do?]* Mentálhigiénés Konferencia BBTE Cluj-Napoca / Gheorgheni, 2012.
13. *Empátiás kommunikáció Alzheimeres betegekkel [Empathic communication with Alzheimer's patients]*/ Mentálhigiénés Konferencia BBTE Cluj-Napoca / Gheorgheni, 2011.
14. *Demens betegek személyközpontú ellátása [Person-oriented care for patients with dementia]*/ Szent István Egyetem, Gödöllő, 2010.